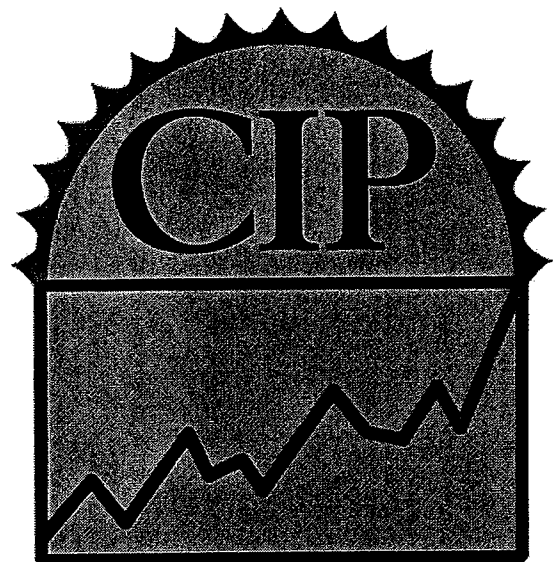


Children/Family Survey

Summary Report 2000



CORE INDICATORS PROJECT

A Collaboration of
the National Association of State Directors of Developmental Disabilities
Services and Human Services Research Institute

HUMAN SERVICES RESEARCH INSTITUTE

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Introduction

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to measure changes in performance over time. In addition, these results permit a state to compare its own performance to that of other states.

The CIP Children/Family Survey was administered for the first time in 1999-2000. Five participating Core Indicator states elected to send out this survey, which was mailed to families of children with developmental disabilities under age 18 and living at home. The five states included Arizona, Minnesota, North Carolina, Utah, and Washington.¹ Results were submitted to HSRI between February and June 2001. For more information about the Core Indicators Project and other reports, please visit our website at: www.hsri.org/cip/core.html.

Children/Family Survey Instrument

In the first two years of CIP, two family surveys were administered to families and/or guardians of adults with developmental disabilities who receive services, both in-home and out-of-home. In the third year of the project, the steering committee decided to begin measuring indicators related to children's services as well as adult services. The original "Family Support Survey" was adapted for families of children under age 18 living at home with their families and named the "Children/Family Survey." This report presents baseline results from the five states who chose to administer this survey in 1999-2000.

Each participating state was asked to mail this questionnaire to 1,000 randomly-selected families who met two criteria: (1) a child under age 18 with a developmental disability was living in the household and (2) either the child or the family was receiving at least one service or support besides case management.² If fewer than 1,000 families met this criteria, the state was instructed to mail the questionnaire to all qualified families. The requirement that questionnaires be mailed to 1,000 families was based on an expected return rate of 40%, which in turn would yield 400 completed questionnaires in hand for each state. Since all states used the standard questionnaire, the results are comparable state-to-state.

Like the surveys for families of adults, the Children/Family Survey addresses general satisfaction with services and supports, as well as targeting issues specific to family involvement, control, and access to necessary services and supports. Additional questions probe areas related to self-determination, such as whether or not the family knows how much money is spent on behalf of their child, and whether they decide how this money is spent. The survey also includes questions pertaining to the outcomes

¹ Nebraska also administered the survey to families with children, but only 14 responses were received. Due to the small sample size, Nebraska's surveys were excluded from this report.

² In Washington, if the participant was receiving early intervention services, they must also have received some other service. This prevented the sample selection from being overly biased toward young children.

of family supports provided, e.g. whether or not the supports received have improved the family's ability to care for their child at home.

The instrument is constructed so that the family member may select from three possible responses to each question ("yes or most of the time", "some of the time", and "no or not at all") or indicate that they don't know the answer or that the question does not apply. The instrument also contains a background information section where the family member is asked to provide certain information about the family and the family member with a disability and to indicate what services and supports are being furnished to the family member and/or the family. Finally, the instrument provides the family member the opportunity to make open-ended comments concerning any topic.

States that administer the Children/Family Survey agree to employ the project's base instrument and questions. If it wishes, a state may include additional questions to address topics not dealt with in the base instrument.

Methodology

Sampling/Administration

States administered the Children/Family Survey by selecting a minimum sample of 1,000 randomly selected families who have a child with a developmental disability living in the family home and were receiving at least one service or support over and above service coordination. Children were defined as age 17 and younger. A sample size of 1,000 was selected with the expectation that the survey return rate would be 40%, yielding 400 usable responses per state. This sampling strategy allows results to be compared across states within a confidence level of $\pm 5\%$. In states where there were fewer than 1,000 potential respondent families, surveys were sent to all eligible families.

Each state entered survey responses into a standard file format and sent the data file to HSRI for analysis. As necessary, HSRI personnel "cleaned" (i.e., excluded invalid responses) based on two criteria:

- The question "Does your family member live at home with you?" was used to screen out respondents who received the survey by mistake. Out of the original 2087 surveys received across the five states, a total of 66 cases were dropped because the respondent indicated that the child did not live at home.
- If the respondent indicated that the child was 18 or older, the response was dropped. An additional 74 cases were removed based on the child's age. The resulting total number of valid surveys was 1947.³

³ Due to unclear wording on the survey, there was some confusion between the questions that asked for the respondent's age and the child's age. In several cases, the respondent indicated his or her own age twice, or reversed the two numbers. In cases where the respondent clearly made an error, we coded the child's age as missing. Cases were excluded only if it was clear that the child was 18 or older. If the age of the child could not be confirmed (i.e. data was missing), the survey was kept in the analysis.

Survey Scope and Response Rates

Washington decided to increase the sample size from required minimum. In addition, Washington constructed its sample to include foster parents of individuals receiving foster care services through the Children's Administration and families of teens being served through the Division of Vocational Rehabilitation rather than only services managed by the Division of Developmental Disabilities.

| Table 1. Number of Surveys Mailed Out and Returned | | | |
|--|----------|------------|-------------|
| | N Mailed | N Returned | Return Rate |
| Arizona | 1000 | 317 | 31.7% |
| Minnesota | 878 | 334 | 38.0% |
| North Carolina | 1049 | 319 | 30.4% |
| Utah | 587 | 337 | 57.4% |
| Washington | 1793 | 780 | 43.5% |
| Total | 5307 | 2087 | 39.3% |

The desired response rate (the percentage of surveys returned versus the number mailed) to these surveys is 40%. Table I estimates the response rates by state, based on the number of returned surveys entered into the database and submitted for analysis, compared to the total number mailed out. Unless noted, these figures do not include the number of "undeliverable" surveys (e.g. those

returned due to incorrect addresses) or surveys that were returned but were excluded from the database for other reasons (e.g. did not meet the state's inclusion criteria). Response rates across states ranged from 30.4% to 57.4%. The overall response rate was reasonable at 39.3%.⁴

Table II shows the number of valid surveys accepted for inclusion in data analysis, overall and by state. Of those returned, over 93% were accepted and included in the data analysis.

| Table 2. Number of Surveys Accepted | |
|-------------------------------------|------|
| Arizona | 260 |
| Minnesota | 314 |
| North Carolina | 285 |
| Utah | 320 |
| Washington | 768 |
| Total | 1947 |

Demographic Profile of Respondents and Family Members with a Disability

Respondents were asked to indicate some basic demographic information about their family and the family member with a disability. Tables 3 and 4 summarize the characteristics of respondents and their family members, in aggregate and by state. When looking at these results, keep in mind that all figures are compiled from self-reported data, and respondents were assured of anonymity.

These demographic data provide a profile of the sample of respondents and their children with disabilities. In particular:

- » 98.4% of all respondents are primary caregivers for the child with a disability.
- » 95.2% of all respondents are parents.
- » 3.9% of all respondents are grandparents (ranging from 1% in Minnesota to 6% in North Carolina).

⁴ It has been suggested that 40% may be too high a return rate to expect. Some states may experience lower return rates due to several factors, including: "survey fatigue," i.e. surveying the population too many times; surveys with additional questions – if the survey is too long people are less likely to fill it out; and the varying accuracy of databases from which the samples are drawn.

- » 21.0% of all respondents reported a household income of below \$15,000. North Carolina reported the highest percentage of families at this income level (32.9%) and Minnesota reported the lowest (10.5%).
- » 77.5% of all respondents described their health as “good” or “excellent,” and 22.6% describe their health as “fair” or “poor.”
- » The average age of respondents across states was 41. Arizona appeared to have a slightly older sample of respondents, with an average age of 44.
- » 20.8% of all respondents have more than one child with a disability in their household.
- » Average age of the child with a disability is 10 years old (the average ranges from 8 in North Carolina to 14 in Arizona).
- » Overall, 62% of all respondents’ children with disabilities are male and 38% are female.
- » 59.6% of all respondents’ children have been diagnosed with MR/DD (ranging from 51.6% in North Carolina to 76.5% in Arizona).
- » 31.6% of all respondents’ children have been diagnosed with a seizure disorder or other neurological problem.
- » 26.3% of all respondents’ children have been diagnosed with cerebral palsy (ranging from 18.2% in Washington to 35.4% in Arizona).
- » 23.6% of all respondents’ children have been diagnosed with autism (ranging from 13.1% in Arizona to 28.8% in Utah).

Services & Supports Utilized by Families

- » Across all states, over two-thirds (71.5%) of families receive specialized services or supports such as mental health care or specialized therapies (e.g., speech, physical, occupational or recreational therapy). Individual states vary in range from 60.5% in UT to 75.8% in AZ.
- » In-home supports (e.g., respite care) are also widely used by families across all states (62.0%). In AZ, approximately half of respondents utilize in-home supports (47.9%), while in MN, 79.9% of families receive in-home supports.
- » Out-of-home supports were utilized, overall, slightly less than in-home supports (42.2%, on average). Results ranged from 36.3% in WA to 57.2% in UT.
- » Overall, 35.6% of all respondents receive SSI payments for their child living at home (ranging from 22.2% in MN to 47.8% in AZ).
- » 27.2% of all families responding receive other financial supports (e.g., cash subsidies). These results range from 13.2% in NC to 46.0% in MN.

- » On average, 14.3% of all respondents receive early intervention services (ranging from 6.4 % in AZ to 32.8% in NC).
- » 12.4% of families, overall, report using transportation services for their child (ranging from 9.7% in UT to 16.3% in NC).

Table 3. Children/Family Survey 2000 -- Demographic Information

| | State: | | ALL | | AZ | | MN | | NC | | UT | | WA | |
|---|--------------------------|--|--------|-----|------------|------|------------|------|------------|------|------------|------|------------|------|
| | Number of valid surveys: | | N=1947 | N % | N=260 | N % | N=314 | N % | N=285 | N % | N=320 | N % | N=768 | N % |
| Is there more than one child with a disability in your household? | | | | | | | | | | | | | | |
| Yes | 397 | | 20.8 | | 36 | 13.9 | 42 | 13.6 | 57 | 21.1 | 67 | 21.8 | 195 | 25.7 |
| How old is your child with a disability? | | | | | | | | | | | | | | |
| Average (Range) | 10 (1-17) | | | | 14 (2-17) | | 10 (1-17) | | 8 (1-17) | | 11 (3-17) | | 9 (1-17) | |
| What is the gender of your child with a disability? | | | | | | | | | | | | | | |
| Male | 1195 | | 62.0 | | 158 | 60.8 | 185 | 59.3 | 168 | 61.1 | 196 | 62.6 | 488 | 63.7 |
| Female | 731 | | 38.0 | | 102 | 39.2 | 127 | 40.7 | 107 | 38.9 | 117 | 37.4 | 278 | 36.3 |
| Has your child been diagnosed with any of the following? (check all that apply) | | | | | | | | | | | | | | |
| Mental illness/psychiatric diagnosis | 123 | | 6.4 | | 26 | 10.0 | 15 | 4.8 | 25 | 8.8 | 15 | 4.8 | 42 | 5.5 |
| Autism | 456 | | 23.6 | | 34 | 13.1 | 85 | 27.2 | 57 | 20.0 | 90 | 28.8 | 190 | 25.0 |
| Cerebral palsy | 508 | | 26.3 | | 92 | 35.4 | 104 | 33.3 | 88 | 30.9 | 86 | 27.6 | 138 | 18.2 |
| Mental retardation/other developmental disability | 1145 | | 59.6 | | 199 | 76.5 | 198 | 63.9 | 147 | 51.6 | 203 | 65.1 | 398 | 52.7 |
| Brain injury | 206 | | 10.7 | | 31 | 11.9 | 36 | 11.5 | 27 | 9.5 | 43 | 13.8 | 69 | 9.1 |
| Seizure disorder/neurological problem | 609 | | 31.6 | | 101 | 38.8 | 110 | 35.3 | 94 | 33.0 | 116 | 37.2 | 188 | 24.8 |
| Chemical dependency | 23 | | 1.2 | | 5 | 1.9 | 1 | 0.3 | 12 | 4.2 | 2 | 0.6 | 3 | 0.4 |
| No disabilities have been diagnosed | 35 | | 1.8 | | 1 | 0.4 | 3 | 1.0 | 17 | 6.0 | 6 | 1.9 | 8 | 1.1 |
| Other disabilities not listed | 601 | | 31.2 | | 65 | 25.0 | 72 | 23.1 | 82 | 28.8 | 113 | 36.2 | 269 | 35.5 |
| About how much help does your child need with daily activities (such as bathing, dressing, eating)? (check one) | | | | | | | | | | | | | | |
| None | 73 | | 3.8 | | 10 | 3.8 | 10 | 3.2 | 9 | 3.3 | 14 | 4.5 | 30 | 4.0 |
| Little | 298 | | 15.6 | | 41 | 15.8 | 46 | 14.8 | 34 | 12.4 | 49 | 15.8 | 128 | 16.9 |
| Moderate | 748 | | 39.1 | | 109 | 41.9 | 102 | 32.9 | 99 | 36.1 | 98 | 31.5 | 340 | 44.8 |
| Complete | 795 | | 41.5 | | 100 | 38.5 | 152 | 49.0 | 132 | 48.2 | 150 | 48.2 | 261 | 34.4 |
| What is your child's race? (check all that apply) | | | | | | | | | | | | | | |
| American Indian/Eskimo/Aleut | 70 | | 3.6 | | 21 | 8.1 | 6 | 1.9 | 4 | 1.4 | 6 | 1.9 | 33 | 4.4 |
| Asian/Pacific Islander | 73 | | 3.8 | | 3 | 1.2 | 18 | 5.8 | 1 | 0.4 | 6 | 1.9 | 45 | 6.0 |
| Black | 156 | | 8.1 | | 11 | 4.2 | 13 | 4.2 | 82 | 28.8 | 3 | 1.0 | 47 | 6.2 |
| White | 1458 | | 75.9 | | 150 | 57.7 | 272 | 87.7 | 178 | 62.5 | 279 | 90.3 | 579 | 76.5 |
| Other/Unknown | 17 | | 0.9 | | 3 | 1.2 | 3 | 1.0 | | | | | 11 | 1.5 |
| Mixed race | 103 | | 5.4 | | 15 | 5.8 | 8 | 2.6 | 16 | 5.6 | 9 | 2.9 | 55 | 7.3 |
| Hispanic | 189 | | 9.8 | | 78 | 30.0 | 6 | 1.9 | 22 | 7.7 | 19 | 6.1 | 64 | 8.5 |
| What is your age? | | | | | | | | | | | | | | |
| Average (Range) | 41 (19-96) | | | | 44 (25-96) | | 40 (24-63) | | 38 (19-73) | | 41 (24-65) | | 41 (20-74) | |

Table 3. Children/Family Survey 2000 -- Demographic Information (continued)

| | State: | | | | | | | | | |
|--|--------|-------|-------|-------|-------|-------|-----|------|-----|------|
| | ALL | AZ | WN | NC | UT | WA | | | | |
| Number of valid surveys: | N=1947 | N=260 | N=314 | N=285 | N=320 | N=768 | | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Are you a primary caregiver for the child with a disability? | | | | | | | | | | |
| Yes | 1874 | 98.4 | 248 | 97.3 | 310 | 99.4 | 267 | 98.2 | 309 | 99.7 |
| How would you describe your health? (check one) | | | | | | | | | | |
| Excellent | 559 | 29.2 | 80 | 30.8 | 94 | 30.2 | 85 | 30.7 | 80 | 25.7 |
| Good | 925 | 48.3 | 128 | 49.2 | 153 | 49.2 | 122 | 44.0 | 160 | 51.4 |
| Fair | 361 | 18.8 | 41 | 15.8 | 55 | 17.7 | 62 | 22.4 | 60 | 19.3 |
| Poor | 72 | 3.8 | 11 | 4.2 | 9 | 2.9 | 8 | 2.9 | 11 | 3.5 |
| What is your relationship to the child with a disability? | | | | | | | | | | |
| Parent (biological, adoptive, or foster) | 1829 | 95.2 | 243 | 93.8 | 308 | 98.7 | 256 | 92.4 | 303 | 97.1 |
| Sibling | 6 | 0.3 | 3 | 1.2 | | | | | 1 | 0.3 |
| Grandparent | 74 | 3.9 | 11 | 4.2 | 3 | 1.0 | 17 | 6.1 | 7 | 2.2 |
| Other relative | 13 | 0.7 | 2 | 0.8 | 1 | 0.3 | 4 | 1.4 | 1 | 0.3 |
| What was the total taxable income last year of the primary wage earners in your household? (check one) | | | | | | | | | | |
| Below \$15,000 | 383 | 21.0 | 68 | 28.5 | 31 | 10.5 | 85 | 32.9 | 43 | 14.5 |
| \$16,000 - \$25,000 | 336 | 18.4 | 56 | 23.4 | 45 | 15.3 | 53 | 20.5 | 45 | 15.2 |
| \$26,000 - \$40,000 | 432 | 23.6 | 44 | 18.4 | 78 | 26.5 | 49 | 19.0 | 90 | 30.4 |
| \$41,000 - \$75,000 | 487 | 26.7 | 48 | 20.1 | 106 | 36.1 | 47 | 18.2 | 92 | 31.1 |
| over \$75,000 | 189 | 10.3 | 23 | 9.6 | 34 | 11.6 | 24 | 9.3 | 26 | 8.8 |
| | | | | | | | | | 82 | 11.1 |

Survey Results by Question

Tables 5 through 9 list the distribution of responses to each question on the Children/Family Survey. The number of valid surveys received from each state is listed at the top of each table. Please note that the figures listed are "valid percents" - meaning that the percents were calculated based on the actual number of people who responded to a particular question. Since not every person responded to every question, the actual N's (number of responses) vary by question.

When looking through these results, it is useful to keep the following in mind:

- Generally, it is better to focus on the “yes or most of the time” and “no or not at all” responses to a question. The response “some of the time” is more difficult to interpret.
- This survey did not include a broad measure of satisfaction. Rather, the questions address various elements of service provision that may contribute to satisfaction but also are important in their own right, especially in furnishing feedback to states concerning the experiences that families are having in their interactions with the public system.
- Broadly, the “all states” aggregate responses to a question constitute benchmarks for comparing states. For example, when a particular state’s proportion of “yes or most of the time” responses is appreciably higher than the all states aggregate average, the quality or characteristic is better reflected in the state’s system than in others. On the other hand, in states where the proportion of “no or not all” responses is appreciably higher than the aggregate, then there is a valid basis for stakeholders to probe further.
- In no instance should the aggregate responses be interpreted as necessarily defining “acceptable” levels of performance or satisfaction. Instead, they are a multi-state “norms” that describe present levels of performance or satisfaction across the five states. Where levels of satisfaction are about the same state-to-state, it means that all states are performing about the same. Where levels of satisfaction are especially high (considerably above the aggregate level) in one or two states, the levels of satisfaction achieved there might define a level of performance that may serve as a guidepost for other states.
- This report displays raw results, that is, the breakdown of responses to each question, for each state and overall. These results are provided so that states can view and compare the detailed responses to each question.

Table 5. Children/Family Survey 2000 -- Information & Planning

| | State: | | | | | | | | | | | |
|---|--------|------|-------|------|-------|------|-------|------|-------|------|-------|------|
| | ALL | | AZ | | MN | | NC | | UT | | WA | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Number of valid surveys: | N=1947 | | N=260 | | N=314 | | N=285 | | N=320 | | N=768 | |
| Do you receive information about MR/DD services and supports that are available to your family? | | | | | | | | | | | | |
| Yes, or most of the time | 760 | 41.4 | 126 | 50.6 | 87 | 32.1 | 101 | 38.4 | 192 | 62.1 | 254 | 34.2 |
| Some, or some of the time | 799 | 43.6 | 103 | 41.4 | 133 | 49.1 | 108 | 41.1 | 104 | 33.7 | 351 | 47.3 |
| No, or not at all | 275 | 15.0 | 20 | 8.0 | 51 | 18.8 | 54 | 20.5 | 13 | 4.2 | 137 | 18.5 |
| If you receive information, is it easy to understand? | | | | | | | | | | | | |
| Yes, or most of the time | 937 | 59.7 | 153 | 66.2 | 122 | 54.0 | 135 | 63.7 | 218 | 73.6 | 309 | 51.1 |
| Some, or some of the time | 556 | 35.4 | 70 | 30.3 | 91 | 40.3 | 74 | 34.9 | 72 | 24.3 | 249 | 41.2 |
| No, or not at all | 77 | 4.9 | 8 | 3.5 | 13 | 5.8 | 3 | 1.4 | 6 | 2.0 | 47 | 7.8 |
| Do you receive information about the status of your child's development? | | | | | | | | | | | | |
| Yes, or most of the time | 651 | 37.2 | 117 | 48.5 | 130 | 44.5 | 142 | 55.5 | 85 | 29.7 | 177 | 26.3 |
| Some, or some of the time | 506 | 28.9 | 73 | 30.3 | 78 | 26.7 | 72 | 28.1 | 108 | 37.8 | 175 | 26.0 |
| No, or not at all | 591 | 33.8 | 51 | 21.2 | 84 | 28.8 | 42 | 16.4 | 93 | 32.5 | 321 | 47.7 |
| If yes, is this information easy to understand? | | | | | | | | | | | | |
| Yes, or most of the time | 730 | 64.5 | 124 | 68.1 | 133 | 66.5 | 148 | 69.5 | 115 | 61.2 | 210 | 60.3 |
| Some, or some of the time | 369 | 32.6 | 56 | 30.8 | 62 | 31.0 | 61 | 28.6 | 69 | 36.7 | 121 | 34.8 |
| No, or not at all | 32 | 2.8 | 2 | 1.1 | 5 | 2.5 | 4 | 1.9 | 4 | 2.1 | 17 | 4.9 |
| Do you get enough information to help you participate in planning services for your child? | | | | | | | | | | | | |
| Yes, or most of the time | 811 | 45.1 | 129 | 51.6 | 144 | 49.1 | 167 | 64.0 | 159 | 52.6 | 212 | 30.6 |
| Some, or some of the time | 611 | 34.0 | 79 | 31.6 | 115 | 39.2 | 55 | 21.1 | 114 | 37.7 | 248 | 35.8 |
| No, or not at all | 376 | 20.9 | 42 | 16.8 | 34 | 11.6 | 39 | 14.9 | 29 | 9.6 | 232 | 33.5 |
| If your family has a service plan, did you help develop the plan? | | | | | | | | | | | | |
| Yes, or most of the time | 1061 | 70.0 | 143 | 69.1 | 199 | 76.8 | 191 | 82.0 | 241 | 82.5 | 287 | 54.7 |
| Some, or some of the time | 279 | 18.4 | 40 | 19.3 | 51 | 19.7 | 25 | 10.7 | 39 | 13.4 | 124 | 23.6 |
| No, or not at all | 176 | 11.6 | 24 | 11.6 | 9 | 3.5 | 17 | 7.3 | 12 | 4.1 | 114 | 21.7 |

Table 5. Children/Family Survey 2000 -- Information & Planning (continued)

| State: | ALL | | AZ | | MN | | NC | | UT | | WA | |
|---|--------|------|-------|------|-------|------|-------|------|-------|------|-------|------|
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Number of valid surveys: | N=1947 | | N=260 | | N=314 | | N=285 | | N=320 | | N=768 | |
| If your family has a service plan, does the plan include things that are important to you? | | | | | | | | | | | | |
| Yes, or most of the time | 1004 | 69.5 | 145 | 73.2 | 190 | 74.2 | 187 | 82.4 | 227 | 79.6 | 255 | 53.2 |
| Some, or some of the time | 327 | 22.6 | 40 | 20.2 | 58 | 22.7 | 30 | 13.2 | 50 | 17.5 | 149 | 31.1 |
| No, or not at all | 114 | 7.9 | 13 | 6.6 | 8 | 3.1 | 10 | 4.4 | 8 | 2.8 | 75 | 15.7 |
| Do [staff/case managers] help you figure out what you need as a family to support your child? | | | | | | | | | | | | |
| Yes, or most of the time | 841 | 47.2 | 133 | 55.6 | 154 | 52.4 | 164 | 63.6 | 205 | 65.7 | 185 | 27.3 |
| Some, or some of the time | 540 | 30.3 | 68 | 28.5 | 96 | 32.7 | 57 | 22.1 | 82 | 26.3 | 237 | 35.0 |
| No, or not at all | 400 | 22.5 | 38 | 15.9 | 44 | 15.0 | 37 | 14.3 | 25 | 8.0 | 256 | 37.8 |
| Do [staff/case managers] talk to you about different options to meet your family's needs? | | | | | | | | | | | | |
| Yes, or most of the time | 750 | 40.9 | 120 | 49.2 | 149 | 49.8 | 147 | 57.4 | 182 | 58.9 | 152 | 20.9 |
| Some, or some of the time | 644 | 35.1 | 87 | 35.7 | 105 | 35.1 | 60 | 23.4 | 94 | 30.4 | 298 | 41.0 |
| No, or not at all | 441 | 24.0 | 37 | 15.2 | 45 | 15.1 | 49 | 19.1 | 33 | 10.7 | 277 | 38.1 |
| Does someone talk to you about the public benefits that are available to you? (e.g. food stamps, EPSDT, Supplemental Security Income, etc.) | | | | | | | | | | | | |
| Yes, or most of the time | 539 | 31.6 | 92 | 41.6 | 102 | 37.4 | 93 | 39.9 | 104 | 34.6 | 148 | 21.9 |
| Some, or some of the time | 445 | 26.1 | 41 | 18.6 | 82 | 30.0 | 33 | 14.2 | 102 | 33.9 | 187 | 27.7 |
| No, or not at all | 720 | 42.3 | 88 | 39.8 | 89 | 32.6 | 107 | 45.9 | 95 | 31.6 | 341 | 50.4 |
| Do [staff/case managers] respect your choices and opinions? | | | | | | | | | | | | |
| Yes, or most of the time | 1317 | 76.7 | 186 | 74.7 | 229 | 81.2 | 200 | 78.4 | 265 | 87.2 | 437 | 69.7 |
| Some, or some of the time | 331 | 19.3 | 51 | 20.5 | 49 | 17.4 | 48 | 18.8 | 35 | 11.5 | 148 | 23.6 |
| No, or not at all | 69 | 4.0 | 12 | 4.8 | 4 | 1.4 | 7 | 2.7 | 4 | 1.3 | 42 | 6.7 |
| Are [staff/case managers] generally respectful, courteous, and knowledgeable? | | | | | | | | | | | | |
| Yes, or most of the time | 1410 | 78.6 | 202 | 80.8 | 238 | 82.9 | 205 | 79.8 | 272 | 87.5 | 493 | 71.4 |
| Some, or some of the time | 318 | 17.7 | 41 | 16.4 | 40 | 13.9 | 39 | 15.2 | 32 | 10.3 | 166 | 24.1 |
| No, or not at all | 67 | 3.7 | 7 | 2.8 | 9 | 3.1 | 13 | 5.1 | 7 | 2.3 | 31 | 4.5 |

Table 6. Children/Family Survey 2000 -- Access to Services and Supports

| State: | ALL | | AZ | | MN | | NC | | UT | | WA | |
|--|--------|------|-------|------|-------|------|-------|------|-------|------|-------|------|
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Number of valid surveys: | N=1947 | | N=260 | | N=314 | | N=285 | | N=320 | | N=768 | |
| Does your family get the services and supports you need? | | | | | | | | | | | | |
| Yes, or most of the time | 773 | 41.7 | 117 | 47.2 | 132 | 43.9 | 137 | 52.1 | 166 | 52.9 | 221 | 30.4 |
| Some, or some of the time | 888 | 47.9 | 107 | 43.1 | 143 | 47.5 | 99 | 37.6 | 136 | 43.3 | 403 | 55.4 |
| No, or not at all | 192 | 10.4 | 24 | 9.7 | 26 | 8.6 | 27 | 10.3 | 12 | 3.8 | 103 | 14.2 |
| Do the supports offered by the MR/DD agency meet your family's needs? | | | | | | | | | | | | |
| Yes, or most of the time | 750 | 42.6 | 117 | 47.6 | 121 | 40.5 | 143 | 55.2 | 172 | 55.8 | 197 | 30.4 |
| Some, or some of the time | 802 | 45.5 | 112 | 45.5 | 131 | 43.8 | 89 | 34.4 | 122 | 39.6 | 348 | 53.6 |
| No, or not at all | 209 | 11.9 | 17 | 6.9 | 47 | 15.7 | 27 | 10.4 | 14 | 4.5 | 104 | 16.0 |
| Are the supports available when your family needs them? | | | | | | | | | | | | |
| Yes, or most of the time | 655 | 37.2 | 101 | 41.2 | 104 | 35.5 | 113 | 44.5 | 143 | 47.8 | 194 | 28.9 |
| Some, or some of the time | 874 | 49.6 | 111 | 45.3 | 147 | 50.2 | 111 | 43.7 | 143 | 47.8 | 362 | 53.9 |
| No, or not at all | 234 | 13.3 | 33 | 13.5 | 42 | 14.3 | 30 | 11.8 | 13 | 4.3 | 116 | 17.3 |
| Have families in your area requested different types of services and supports be made available in your area? | | | | | | | | | | | | |
| Yes, or most of the time | 305 | 45.7 | 44 | 47.3 | 55 | 49.5 | 46 | 40.7 | 63 | 47.0 | 97 | 44.7 |
| Some, or some of the time | 188 | 28.1 | 18 | 19.4 | 34 | 30.6 | 29 | 25.7 | 44 | 32.8 | 63 | 29.0 |
| No, or not at all | 175 | 26.2 | 31 | 33.3 | 22 | 19.8 | 38 | 33.6 | 27 | 20.1 | 57 | 26.3 |
| If yes, was the State responsive to their requests? | | | | | | | | | | | | |
| Yes, or most of the time | 104 | 26.1 | 21 | 38.2 | 17 | 22.1 | 20 | 33.9 | 29 | 36.3 | 17 | 13.3 |
| Some, or some of the time | 176 | 44.1 | 24 | 43.6 | 43 | 55.8 | 25 | 42.4 | 42 | 52.5 | 42 | 32.8 |
| No, or not at all | 119 | 29.8 | 10 | 18.2 | 17 | 22.1 | 14 | 23.7 | 9 | 11.3 | 69 | 53.9 |
| If you have ever asked the MR/DD agency for assistance in an emergency or crisis, was help provided to you right away? | | | | | | | | | | | | |
| Yes, or most of the time | 287 | 32.2 | 52 | 36.1 | 41 | 28.7 | 32 | 27.4 | 72 | 50.0 | 90 | 26.2 |
| Some, or some of the time | 204 | 22.9 | 42 | 29.2 | 37 | 25.9 | 26 | 22.2 | 32 | 22.2 | 67 | 19.5 |
| No, or not at all | 401 | 45.0 | 50 | 34.7 | 65 | 45.5 | 59 | 50.4 | 40 | 27.8 | 187 | 54.4 |

Table 6. Children/Family Survey 2000 -- Access to Services and Supports (continued)

Table 8. Children/Family Survey 2000 -- Satisfaction with Family Supports

| State: | | | ALL | | | AZ | | | MN | | | NC | | | UT | | | WA | | |
|--|------|------|--------|------|-----|-------|-----|------|-------|------|-----|-------|---|---|-------|---|---|-------|---|--|
| Number of valid surveys: | | | N=1947 | | | N=260 | | | N=314 | | | N=285 | | | N=320 | | | N=768 | | |
| | N | % | N | % | | N | % | N | % | N | % | N | % | N | % | N | % | N | % | |
| Do you feel that family supports have helped you to keep your child at home? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 1114 | 70.1 | 121 | 61.4 | 206 | 71.8 | 160 | 74.4 | 241 | 85.5 | 386 | 63.4 | | | | | | | | |
| Some, or some of the time | 271 | 17.0 | 37 | 18.8 | 57 | 19.9 | 28 | 13.0 | 26 | 9.2 | 123 | 20.2 | | | | | | | | |
| No, or not at all | 205 | 12.9 | 39 | 19.8 | 24 | 8.4 | 27 | 12.6 | 15 | 5.3 | 100 | 16.4 | | | | | | | | |
| Do you feel that family supports have made a positive difference in the life of your family? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 1206 | 68.6 | 120 | 56.1 | 198 | 66.7 | 180 | 73.5 | 258 | 85.4 | 450 | 64.2 | | | | | | | | |
| Some, or some of the time | 413 | 23.5 | 69 | 32.2 | 76 | 25.6 | 49 | 20.0 | 34 | 11.3 | 185 | 26.4 | | | | | | | | |
| No, or not at all | 140 | 8.0 | 25 | 11.7 | 23 | 7.7 | 16 | 6.5 | 10 | 3.3 | 66 | 9.4 | | | | | | | | |
| Do you feel that family supports have improved your ability to care for your child? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 1152 | 65.8 | 114 | 53.0 | 194 | 65.3 | 171 | 70.4 | 246 | 82.3 | 427 | 61.3 | | | | | | | | |
| Some, or some of the time | 398 | 22.7 | 63 | 29.3 | 73 | 24.6 | 45 | 18.5 | 43 | 14.4 | 174 | 25.0 | | | | | | | | |
| No, or not at all | 201 | 11.5 | 38 | 17.7 | 30 | 10.1 | 27 | 11.1 | 10 | 3.3 | 96 | 13.8 | | | | | | | | |
| Has your child experienced a serious injury in the past year? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 118 | 6.8 | 19 | 8.2 | 16 | 5.7 | 17 | 7.4 | 22 | 7.3 | 44 | 6.3 | | | | | | | | |
| Some, or some of the time | 42 | 2.4 | 5 | 2.1 | 9 | 3.2 | 4 | 1.7 | 10 | 3.3 | 14 | 2.0 | | | | | | | | |
| No, or not at all | 1582 | 90.8 | 209 | 89.7 | 257 | 91.1 | 210 | 90.9 | 268 | 89.3 | 638 | 91.7 | | | | | | | | |
| Have you been informed of your agency's grievance process? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 509 | 33.3 | 94 | 42.9 | 115 | 45.3 | 79 | 38.2 | 100 | 41.0 | 121 | 20.0 | | | | | | | | |
| Some, or some of the time | 176 | 11.5 | 32 | 14.6 | 37 | 14.6 | 20 | 9.7 | 29 | 11.9 | 58 | 9.6 | | | | | | | | |
| No, or not at all | 844 | 55.2 | 93 | 42.5 | 102 | 40.2 | 108 | 52.2 | 115 | 47.1 | 426 | 70.4 | | | | | | | | |
| Are you satisfied with the way complaints or grievances are handled and resolved by the state agency? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 261 | 39.3 | 50 | 45.9 | 40 | 35.1 | 61 | 45.5 | 55 | 61.8 | 55 | 25.2 | | | | | | | | |
| Some, or some of the time | 203 | 30.6 | 32 | 29.4 | 42 | 36.8 | 42 | 31.3 | 22 | 24.7 | 65 | 29.8 | | | | | | | | |
| No, or not at all | 200 | 30.1 | 27 | 24.8 | 32 | 28.1 | 31 | 23.1 | 12 | 13.5 | 98 | 45.0 | | | | | | | | |
| Are frequent changes in support staff a problem for your family? | | | | | | | | | | | | | | | | | | | | |
| Yes, or most of the time | 432 | 27.0 | 68 | 29.8 | 101 | 36.5 | 63 | 27.5 | 40 | 15.0 | 160 | 26.7 | | | | | | | | |
| Some, or some of the time | 492 | 30.8 | 76 | 33.3 | 92 | 33.2 | 69 | 30.1 | 95 | 35.7 | 160 | 26.7 | | | | | | | | |
| No, or not at all | 676 | 42.3 | 84 | 36.8 | 84 | 30.3 | 97 | 42.4 | 131 | 49.2 | 280 | 46.7 | | | | | | | | |

Table 9. Children/Family Survey 2000 -- Community Connections

| | STATE: | | ALL | | AZ | | MN | | NC | | UT | | WA | |
|--|--------|------|------|--|-----|------|-----|------|-----|------|-----|------|-----|------|
| | N | % | 1947 | | N | % | N | % | N | % | N | % | N | % |
| Number of valid surveys: | | | | | | | | | | | | | | |
| If you want help getting family supports in your community (such as services offered through recreation departments or churches), do [staff/case managers] help connect you to these services? | | | | | | | | | | | | | | |
| Yes, or most of the time | 450 | 29.2 | | | 78 | 40.2 | 64 | 26.9 | 75 | 36.8 | 89 | 39.2 | 144 | 22.4 |
| Some, or some of the time | 460 | 30.5 | | | 67 | 34.5 | 76 | 31.9 | 46 | 22.5 | 75 | 33.0 | 196 | 30.4 |
| No, or not at all | 597 | 39.6 | | | 49 | 25.3 | 98 | 41.2 | 83 | 40.7 | 63 | 27.8 | 304 | 47.2 |
| If you want help making arrangements with family, friends, or neighbors who can provide some of the supports your family needs, do [staff/case managers] help you do this? | | | | | | | | | | | | | | |
| Yes, or most of the time | 334 | 23.2 | | | 46 | 27.9 | 56 | 22.8 | 63 | 32.3 | 84 | 35.9 | 85 | 14.1 |
| Some, or some of the time | 292 | 20.2 | | | 42 | 25.5 | 52 | 21.1 | 35 | 17.9 | 54 | 23.1 | 109 | 18.1 |
| No, or not at all | 816 | 56.6 | | | 77 | 46.7 | 138 | 56.1 | 97 | 49.7 | 96 | 41.0 | 408 | 67.8 |
| Do you feel that your family has access to community activities? | | | | | | | | | | | | | | |
| Yes, or most of the time | 657 | 37.0 | | | 102 | 45.3 | 107 | 36.3 | 107 | 43.0 | 125 | 41.4 | 216 | 30.6 |
| Some, or some of the time | 795 | 44.7 | | | 91 | 40.4 | 139 | 47.1 | 87 | 34.9 | 131 | 43.4 | 347 | 49.2 |
| No, or not at all | 325 | 18.3 | | | 32 | 14.2 | 49 | 16.6 | 55 | 22.1 | 46 | 15.2 | 143 | 20.3 |
| Does your child participate in community activities? | | | | | | | | | | | | | | |
| Yes, or most of the time | 367 | 19.6 | | | 67 | 26.7 | 51 | 16.9 | 60 | 22.2 | 60 | 19.4 | 129 | 17.5 |
| Some, or some of the time | 834 | 44.6 | | | 105 | 41.8 | 156 | 51.7 | 110 | 40.7 | 154 | 49.7 | 309 | 41.9 |
| No, or not at all | 670 | 35.8 | | | 79 | 31.5 | 95 | 31.5 | 100 | 37.0 | 96 | 31.0 | 300 | 40.7 |
| Does your child spend time with children who do not have developmental disabilities? | | | | | | | | | | | | | | |
| Yes, or most of the time | 1010 | 53.2 | | | 143 | 56.3 | 146 | 47.1 | 170 | 62.0 | 161 | 51.3 | 390 | 52.1 |
| Some, or some of the time | 736 | 38.7 | | | 93 | 36.6 | 131 | 42.3 | 89 | 32.5 | 128 | 40.8 | 295 | 39.4 |
| No, or not at all | 154 | 8.1 | | | 18 | 7.1 | 33 | 10.6 | 15 | 5.5 | 25 | 8.0 | 63 | 8.4 |
| Can you contact your family member's [staff/case managers] whenever you want to? | | | | | | | | | | | | | | |
| Yes, or most of the time | 1193 | 65.7 | | | 168 | 68.3 | 213 | 72.4 | 204 | 75.0 | 223 | 75.1 | 385 | 54.5 |
| Some, or some of the time | 517 | 28.5 | | | 68 | 27.6 | 70 | 23.8 | 49 | 18.0 | 65 | 21.9 | 265 | 37.5 |
| No, or not at all | 106 | 5.8 | | | 10 | 4.1 | 11 | 3.7 | 19 | 7.0 | 9 | 3.0 | 57 | 8.1 |

Discussion of Results

In this section, we summarize the survey findings in aggregate (i.e., results for all participating states combined). Responses to questions are organized by topic area (e.g., information, support planning, satisfaction, etc.) for ease of review.

Information

- » 85.0% of families indicate that they receive information “some” or “most” of the time about the MR/DD services and supports available to their family.
- » 95.1% of the families state that the information they receive is easy to understand.
- » Approximately two-thirds (66.1%) of families receive information “some” or “most” of the time regarding their child’s development. One-third indicated that they do “not at all” receive this information.
- » For those who do receive information about their child’s disability, nearly all (97.1%) find the information easy to understand.

Support Planning/Support Coordination

- » Approximately half (45.1%) of families feel they get enough information to help them participate in service/support planning for their child. Another one-third (34.0%) get enough information “some” of the time, and 20.9% indicated “no”, they do not have enough information to participate in their child’s service/support planning.
- » For those families who do have a service/support plan, 88.4% indicated they do help in developing their family’s plan “some” or “most” of the time.
- » 69.5% of families with a service plan state that their family’s plan includes things important to them. 22.6% respond that their plans sometimes include things important to them, while 7.9% say that their plan does not at all include things important to the family.
- » Nearly half (47.5%) of families indicate that their staff/case manager helps them all or most of the time to figure out what supports the family needs. One-third of families (30.3%) state that staff help them “some” of the time, while one-quarter (22.5%) find that staff are not helpful in this area.
- » About three-quarters of families (76.0%) feel that their case managers/support coordinators discuss with them a variety of options for meeting their families needs “some” or “most” of the time. The remaining quarter (24.0%) do not feel that available options are discussed with their family.
- » 57.7% of families indicate that their case manager/support coordinator talks with them about the public benefits (e.g., food stamps, SSI) available to their family (31.6% indicate “yes”, 26.1% indicate “sometimes”). However, 42.3% of families have not discussed these options benefits with families.

- » Nearly all families (96%) feel that their case manager/support coordinator respects the family's choices and opinions, and are generally respectful, courteous and knowledgeable (96.3%).

Access to Services & Supports

- » 41.7% of families state that they usually get the services and supports they need. 47.9% indicate that they sometimes receive needed services and supports, with the remaining 10.6% responding that they do not get the services and supports their family needs. When asked if supports offered through the state's MR/DD agency meet family needs, responses were very similar (42.6% indicate "yes/most of the time", 45.5% "some of the time", and 11.9% "no/not at all").
- » Overall, an extremely high number of families (92.6%) report that they have access to health services for their child "most of the time."
- » Just over one-third of families (37.2%) state that supports are available when their family needs them. Half of the families responding (49.6%) say that supports are only sometimes available when needed, and 13.3% say they are not available when needed.
- » In an emergency or crisis, supports are somewhat less available. When asked if MR/DD supports were available right away during an emergency, one-third of families (32.2%) indicated "yes, most of the time". An additional 22.9% stated that supports were available some of the time, and nearly half (45.0%) said that supports were not available immediately during a crisis or emergency.
- » 73.8% of respondents state that they or other families in their area have requested that different types of services and supports be made available in their area. Among these families, 26.1% indicate that the State was responsive to their requests "most of the time", 44.1% responded "some of the time", and 29.8% said the State was not responsive to their requests.
- » Of the families for which English is not their first language, 64.5% state that staff translators were available "most of the time" to talk with them in their preferred language. Another 16.3% had translators available "some of the time", and the remaining 19.3% indicated that staff and/or translators were not available.
- » Among the families who have a child who does not speak English or who uses a different way to communicate (e.g., sign language), one-third of respondents stated that staff were available to communicate with their child "most of the time", one-third indicated that staff were available "some of the time", and another one-third stated that staff were "not at all" available to communicate effectively with their child.

Choice & Control

- » 84.7% of respondents choose the agencies or providers that work with their family some or most of the time. 15.3% do not choose the provider/agency that works with their family.
- » Slightly fewer, 73.1%, of families choose the support staff that work directly with their family (some or most of the time), while 26.9% do not choose their family's support workers.

- » 87.3% of respondents would like at least some control over the hiring and management of their support workers, yet only 67.2% feel they have “some” or more control over this hiring and management.
- » 37.9% of families know how much money is being spent by the MR/DD agency on their child’s behalf. 43.3% have no information in this matter.
- » 32.6% of families decide how this money is spent “most of the time”, 30.4% decide “some of the time”, and 37.0% indicate that they do not have any control over how this money is spent.

Satisfaction with Family Supports

- » 87.1% of families feel that the supports they receive have, to some extent, helped them to keep their child at home.
- » 92.1% of families state that family supports have made a positive difference in their family’s life.
- » 88.5% of respondents state that family supports have improved their ability to care for their child.
- » Fewer than half (44.8%) of families are familiar with their agency’s grievance procedures. For those families who have had complaints or grievances, 69.9% are satisfied with the way they have been handled, while 30.1% have been unsatisfied.
- » 57.8% of families indicate that frequent changes in support staff are a problem for their family. 42.3% state that this is not a problem.

Community Connections

- » Most families (81.7%) feel their family has access to community activities at least some of the time. However, 35.8% indicate that their child does not participate in community activities.
- » About half (53.2%) of respondents say their child spends “most” of his/her time with other children who do not have developmental disabilities. 38.7% spend “some” time with children who do not have disabilities, and 8.1% of children do not spend any time with non-disabled children.
- » 59.7% of families indicated that their support coordinator/case manager would help them connect to community supports (e.g., services offered through local parks and recreation) “some” or “most” of the time if they wanted. 39.6% said “no”, their case manager would not help them make these connections.
- » 43.4% of families said their case manager/support coordinator would help them make necessary arrangements with family, friends or neighbors who could provide supports to their family. 56.6% stated that their case manager would not help in this regard.

- » 94.2% of families indicated that their support coordinator/case manager could be contacted “some” of “most” of the time when the family wanted.

Qualitative Results: Analysis of Comments

Like the other CIP family surveys, the Children/Family Survey includes a page at the end for respondents to record comments. To summarize these responses, we used the qualitative analysis software program QSR NUD*IST to tally and collate all comments related to certain topic areas. This program allows the user to search for certain key words related to various topics. For example, to find all comments related to case managers, we set the program to look for the terms “case manager or case worker or coordinator.” We then chose the most frequently mentioned 5-6 topics, and organized them most frequent to least frequent.

Within each topic area, we read all comments related to that topic and wrote a few sentences summarizing the general themes and ideas present. In addition, we pulled out some quotes that were representative of the majority of comments, some that were representative of lesser themes, and some that seemed interesting because they presented an innovative idea or unique way of looking at things. What you will read in the next several pages are these brief summaries and selected quotes, by topic area, for each state.

*CFS Comments 2000: What People Are
Talking About in... Arizona*

**Case
Managers:**

Most comments praised case workers for providing excellent care, and being enthusiastic, caring, and helpful. Several respondents expressed that high turnover rate is a problem with case managers. A few negative comments concerned complaints that the case manager was not competent or reliable.

"Our case worker is excellent!!!"

"The biggest problem we have experienced is turnover with case managers."

"In my child's case the thing that really bothers me is we get a new case worker every 6 months or so."

"We have had at least 10 case managers in 12 years. Changing case managers is the hardest."

"We finally have an enthusiastic support coordinator who is always willing to go out of her way for us!"

"My present Support Coordinator is very helpful and professional."

Respite:

Several people commented that respite care workers are not adequately paid, and that there are not enough qualified respite workers. Other comments indicated that there are not enough respite providers and that respite is not available.

"The therapies she receives are helpful, but respite is probably the service we need the most."

"The biggest problem I've had for the last 8 years is the availability of providers for respite."

"Problems that our family has: 1) no reliable respite sitter; 2) music therapy was denied."

"We have problems finding qualified respite providers. No one wants to work for such little pay. They either do a lousy job or the good ones move on to other things."

Information:

Some people thanked their case workers and providers for providing information. Others commented on lack of information, or requested information on specific things such as job training, SSI money, sex education, transition, group homes, wheelchair friendly churches, and general information about services available.

"Would like information on transitioning to a group home. Need information on job training."

"My son's social worker has always been helpful & supportive. He keeps me informed of other services and activities available to us."

"How can we get information. Sometimes I feel like I'm running in circles."

Staff:

There were several comments about the problem of frequent changes in staff and lack of staff. A few comments expressed appreciation for the helpfulness of staff.

"There are not many employees to support people [in] the areas they need it the most (respite & hab)."

"I think the staff is helpful to their best ability but are limited as to what they can do."

"I am very thankful for all the agency, and staff, PLS and case manager's for all the help they have given us."

Health:

A few people expressed the need for nurses for medical respite, availability of medical equipment, and for home health care.

"We have to travel 2 hours for medical equipment (i.e. kneebraces that can only be obtained in the next town 30 miles away)."

"We do not have enough nurses to provide medical respite for our children. Most are not qualified to help with our specialized home health needs."

*CFS Comments 2000: What People Are
Talking About in... Minnesota*

**Case
Managers:**

For the most part, people seem to be happy with their case managers. Most comments praised case managers and expressed appreciation for the work they are doing. A few commented on uncooperative case managers and high turnover rates.

"Our case worker is usually always available to us and if she/he should be away, someone else will answer or she/he will call back shortly."

"I feel I have been very fortunate to have had two excellent county case managers. However, I work for two different Family Support programs and know this is an exception."

"We have had 3 case managers in the last 2 years."

"Our family has been very well served by Hennepin county DD case managers. Only 2 in 10 years!"

Staff/PCAs:

Personal Care Attendants (PCAs) in Minnesota seem to be a real problem. Almost all comments about PCAs note how difficult it is to find and keep PCAs. Some comments note that PCAs are underpaid, while others state that there simply are not enough trained individuals to meet the needs of families.

"My on-going issue is the ability to hire and maintain PCA's."

"We desperately need to improve PCA help. Our company (choices for children), cannot get us enough PCA hours covered. The pay for PCA's is not competitive with the job market."

"Our family has been without PCA help for over 5 weeks. Our case worker has been helping, but because of low pay to the PCA's we have limited persons applying for the job. Someone needs to be aware of this crisis in this county of low paying PCA's."

"Our experience is that the in-home waiver care providers are generally college women and they generally stay 2-4 months and then leave for a better paying job or because their class schedule changes."

Money:

Several comments were directed at how money flows to services. Many parents would like to have more control over the money that is being spent on their son or daughter. Several feel that they could spend the money more effectively and efficiently than the current providers. Some also commented that PCA's should be paid more.

"I would like more control and support staff and know how money is being spent. In most cases, I can find better help on my own."

"Personal care attendants need to earn more money to attract more coverage and better quality staff."

"We want our daughter to live at home. I would like a system where we would have money given to us so that we could use it for her needs ourselves."

"Eliminate the middleman, such as the service provider of PCA's. They do not have staff at all for my son. I have to find my own PCA and send them to the agency. The agency makes money off my son and really provides no necessary service."

Information: Comments on information seem to be split fairly evenly between those who are satisfied with the information they are receiving, and those who are frustrated because the information is hard to understand, or they are not getting enough of it. Things that people would like more information on include: Medicaid, services, options, planning, accessible churches, and some odds and ends like computer games and books.

"We are pleased with the case management services, it has been helpful to us. He fills all the needs of information we need."

"Our case worker is usually unaware of services and options. When we ask him about available service, he is discouraging and always refers to how much paper work would be involved. When we do receive requested info from him, it is usually incomplete."

Health Services: The majority of comments refer to the lack of attendant care or poor quality of attendant care workers. Other comments include the difficulty of dealing with the Medicaid system and the difficulty of obtaining medical information.

"We have been very frustrated the last 2-3 years with the availability of nursing services. Because of the poor reimbursement rate for medical assistance, the homecare agencies have been unable to keep up with the rate of pay offered by hospitals and clinics."

"Personal care attendants need to earn more money to attract more coverage and better quality staff. Agencies will take almost anyone that can walk to care for a very difficult child."

"Health insurance/MA and medicare are the big issues that have continued to be an issue. County workers tend to treat case as if just another "welfare" case rather than a family dealing with complex health issues and the costs related to this."

Respite: Several people commented that respite care is hard to get, respite workers are hard to find and there are not enough qualified workers. However, those that are able to get respite seem to be satisfied with it.

"Our case manager is not the problem. It is the lack of trained staff for any kind of respite."

"Services are available to us for PCA care and respite care. But I have to find my own workers and respite care was nonexistent until the county gave us funding to pay our own people."

Wait Lists: Waiting lists for waiver services seem to be quite long. All comments on wait lists seemed to indicate that they are unacceptably long.⁵

“We have a 10yr old severely retarded daughter who has been on a waiting list for 5 years for a waiver. Why does it have to take so long?”

Family Support: Comments are from people who are getting family support but would like more, or would like more people to know about it.

⁵ It is worthwhile to note that Minnesota enrolled 5,537 new people on the DD Waiver during an enrollment period that occurred approximately 9 months after the Children/Family Survey was completed by families.

*CFS Comments 2000: What People Are
Talking About in... North Carolina*

**Case
Managers**

Some comments praise case managers for being wonderful and supportive, but many of these qualify their praise by saying how little information case managers have or how confusing the waiver and/or service system is. Other comments focus on the problem of high turnover of case managers, and the burden this places on family members to find their way through the system on their own.

"My services coordinator, while nice, does not always have accurate and complete information."

"The more I learn about the CAP waiver the more amazed I am at the wonderful job our case manager and providers are able to do under the burden of the waiver's complex regulation."

"With the constant turnover of case managers, it's hard to create the cooperative relationship between services available and client needs."

"We have had 3 or 4 changes in case managers during the past 1 1/2 years. We do not even know who ours is at this time. But I work in the system, so I am able to take care of things when needed."

Information

Several comments noted lack of information being circulated regarding children's services and low income supports. Some case managers are not well-informed, and information does not seem to be distributed to parents. The best way for parents to get information seems to be through networking with other parents.

"Getting the information regarding what services were available once my child was injured which was not easy at all. The rehabilitation social workers did not plug us in at all. A fellow parent got us started in the right direction."

"Staff/case managers are very supportive, but have no information about financial support for low income families with developmentally disabled children [such as information about SSI and food stamps]."

"My daughter is now in Smart Start through the school system. I was happier with her teachers when she was in the Early Intervention Program. But this program stopped when she turned 3 years old. Please send me some information about things I can do to help my little girl. Smart Start here doesn't seem to help."

Staff

Turnover of staff seems to be a concern to many people in North Carolina. Some people are pleased with the services they are receiving, but many more would like to see more

consistent, quality care workers.

"Need to make sure staff is doing their job and doing it right. Staff has too much freedom. Need to check on staff more often. Staff shouldn't be allowed to bring other people to work with them. They are there to work with clients not to socialize. Staff shouldn't be allowed to stay on the phone. Client needs should come first."

"I wish that support staff would get people to stay or sign a contract for one year service with the company. So that the child would get to know them. They come and go so fast. 3 month or a week."

"So far I have been well pleased with all the help they have tried to help me and my family with. When you have a child that is mental challenge and also very hyperactive you need all the help you can get. Also I have other children in the home so I have a demanding time frame in the day. Thank you so very much for everything your staff have done for me and my family."

"[The provider agency] needs to be eliminated so that more monies will go to the staff that work directly with these children."

Respite

Some are pleased with respite, some are not pleased, and some are not getting respite at all. For those that are not pleased, a large portion of the problem seems to be the difficulty of finding quality care givers, and other problems associated with high turnover rates.

"We are well pleased with the supported living and respite services we receive through the CAP program. We have all worked together to plan supported living goals to reinforce our son's IEP goals. Slowly but consistently we are blessed with progress in his motor and self help skills as well as cognitive and receptive language development."

"Most of the problems that we encounter are finding good, qualified candidates to provide CAP training and or respite services. The turnover in that area is tremendous. Not sure if the wages they receive is the problem or what most of the time you just settle for someone or no one at all."

"Some people say that there are some families who can get paid for taking care of your child if you go on vacation or maybe need someone for a day. I was denied this benefit. Why do some counties do this and some don't?"

Health Care

Some comments were from people satisfied with medical services, others were from people who were frustrated with their inability to get affordable services, especially dental services.

"I am very glad we live in X County where my son has access to good schools, hospitals, doctors, special programs and opportunities for people with disabilities."

"My child is currently involved in the CAP/MR/DD and due to this he can't enroll in any of the healthcare programs that are w/Medicaid. I have to find doctor's on my own who will

take Medicaid. This has become a major headache and I feel that my child is being discriminated."

"I feel dental care is a serious problem. Medicaid doctors are plentiful but not so with dentist. Dental care is important and needs more attention."

*CFS Comments 2000: What People Are
Talking About in... Utah*

Respite: Most comments on respite were from people who are pleased with the respite services they are receiving. Several even inferred that keeping their child at home would not be possible without respite. However, a few people expressed that they need to get respite services, or need to more respite hours.

"We've been very happy with services provided through DSPD. I don't know what we'd do with out respite!"

"We are in desperate need of community support here in Tooele, i.e. adaptive parents, tutoring, respite care, summer programs, help with the school dist., etc. Many parents of young children here feel we have no support but each other. HELP!"

Support Coordinators: Some comments were from people who really appreciate the support given to them by their support coordinators, who check in with them often and are very good at helping them find the services they need. Other comments included complaints about the lack of professionalism of support coordinators and the difficulty in dealing with frequent turnover.

"We are very happy with our support coordinator. She calls often to see how things are going. She comes to my house for appointments which is very convenient for me. She visits the school frequently to see how he is doing in his school program."

"The only other thing I would like to is to have more regular contact with my support coordinator."

"The most annoying thing I have experienced with support from DSPD is the constant change is support personnel. It seems like we have had a different one about every year. Actually we are on our 4th support coordinator."

Family Support: Most comments were very positive about and grateful for Family Support. Some people commented that it is difficult and frustrating to try to find and keep good support staff.

"We have been very happy with family support services and very fortunate to be able to receive this help."

"If I didn't have family support we would no longer be a family and my children would have had to be placed outside the home. Family support has saved my life."

"We receive funding from DSPD for family support, but have not had much success in identifying individuals who are able to provide services! It's great to have the funds, but if you can't find anyone to provide services, it's very frustrating."

Information: Most comments were about need for more information on services, and the need for a better information delivery system in general. A few people were happy with the information provided to them by their case managers.

"Sometimes recreational or other opportunities come up; it would be a benefit of DSPD or family council could put out quarterly flyers that would inform parents of these up coming programs."

"I am disgusted that parents with children having special needs have to become overnight researchers and extract program information from state agencies instead of these agencies fully disclosing programs and funding available."

Wait List: Some people complain of being on a wait list, others are happy with services but worry about their friends who are still on a wait list.

"We were on the waiting list for 3 years. When I remember those years, I can't believe I made it through them. When you are physically and mentally exhausted, you just live day to day, with no goals or plans."

Education: A few comments were made about the difficulty of getting what is needed from the school system.

"In a rural community a person needs to be a pioneer in a lot of areas especially dealing with school districts example, providing education aids to help teach braille acquiring brailers."

*CFS Comments 2000: What People Are
Talking About in... Washington*

**Case
Managers:**

Some comments show that people are happy with and grateful for the support their case manager provides, but many other comments indicate that many case managers are too busy to give adequate attention to everyone on their case load. Several people expressed that they are frustrated by their lack of responsiveness or effectiveness.

"Our case manager is wonderful and hopefully we don't ever change. I am satisfied with him completely but if something should happen and he can no longer be our case manager, I would prefer choosing our own."

"Our case manager is very busy, but takes care to call us back and works well with us."

"I don't even know who the case manager is for my son. Once a year we are contacted by letter stating how much family support dollars there are available for my son and that's it."

"I have twin boys that are on DDD. I wish there was more funding, so there would be more case managers. They are overworked so that means they can't spend more time with families that are on their caseload. Things tend to fall through the cracks."

"My child's case manager has too many cases to spend much time dealing with my child's issues, although he is kind and courteous."

Respite:

Many people are frustrated by not being able to find respite providers, not receiving enough information about respite and respite providers, and not being able to use respite dollars in a more flexible manner. Almost everyone is grateful for the services they are receiving, but would appreciate more assistance in using respite.

"There is a critical shortage of respite care providers. We are allocated Medicaid personal care hours but have not used any to date because we cannot find a qualified respite care provider."

"We use respite care babysitters and we appreciate being able to hire them through our daycare and they get them cleared/certified through DSHS. Thanks for your support."

"The only complaint I have, if any, is the usage of respite care hours. With the restriction of signing contract with the state (even FBI fingerprints if less than 3 years of residence in WA) getting their respite care paycheck a few months later, etc. makes it so difficult to find a respite-care provider. This process needs dramatic improvement!"

"I think I should be able to use my Medicaid personal care funds for my son to be watched in other places besides my home. Restricting these funds to only my home makes it much harder to use these funds. It's hard to find someone to come into my home."

"My respite care providers that work best are 16-19 year old males. My child with special needs is male. Because of the age limits I can only use my DDD money on the older boys. These boys provide excellent care and make great role models for my son."

Information: Almost all comments about information focused on lack of information given to parents, and the difficulty of determining what services are available and how the DD system works in general.

"When I was desperately searching for a source for secretin as a remedy for autism I was dismayed to learn that the state had been funding the medication for some autistic children but no one gave that information to all of the DDD autistic clients. By the time I learned that DDD was paying for secretin they had already been told they couldn't provide funding for secretin anymore. I felt cheated and that I was not being dealt with fairly."

"It is very challenging and tough to learn how the current system works. In our case, we never did get a clear picture of all the options available for our disabled son. DDD appears to not want to volunteer any information that has monetary implications. We found out about a lot of services by networking with other parents and then going back to our case provider and requesting those services. DDD doesn't appear to have or want to share, all the services available to the disabled."

Health Services: Most comments focused on the difficulty of understanding the system, the need for more information, or the difficulty of getting services needed within the system (using medical coupons). Several people requested coverage of specific kinds of care such as: Chiropractic, Naturopathic, and Psychiatric.

"We have not even used much of the money my son has available. By the time I get doctors statements and all the letters from them to get an ok to use the funds it's a long time before I get the exact letter they need. I've had to go back and call my son's medical workers 10 times or more, get letter after letter basically saying the same thing before they are satisfied enough to buy certain items. We give up a lot it's just so hard to get things ok'd to buy items."

"The biggest obstacle I encounter is service providers who won't accept the medical coupon if my primary insurance rejects coverage. Their comment is that it takes too long to get reimbursed by the state. Because of this our child has had to go without needed therapies for periods of time."

Family Support: Most comments about family support note how long it takes to get it. Many feel they had to wait too long. Of those who have it, some are satisfied, but many wish there was more money available and that it could be used in a more flexible manner.

"We are very grateful for the DDD family support program which has helped us to buy many things for our severely handicapped daughter which were not covered by insurance."

"The current system is not responding to families needs. Example, the family support opportunity has too many limitations on how money can be spent. MPC can only be used in home."

"I am satisfied with the extent my caseworker has gone to provide emergency funds for my son's services, however, I have been waiting almost 2 years to receive family support services and that seems very excessive! Very frustrating!"

Education:

Some comments about wanting more support for educational assistance that the school system is not providing. Some comments from people satisfied with the support from the school system they are getting.

"Support services through Seattle School District for preschool, speech, physical therapy is good."

"I believe the funds should be available to provide at home help to keep educational goals ongoing. Schools just can't provide all educational needs for these kids."

"I still don't clearly understand how to get educational equipment for my child and the limitations and basic instructions on how to take advantage of the assistance. Even my child's teachers sent a request that was denied but with no explanation why or how to get the equipment needed to assist my child fully."